North American Collaborating Center ICF Newsletter

May, 2008

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 Please join us August 26-27 in Québec City for this year's ICF Conference!
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 - Special invitation to persons in the western U.S. who are involved in rehabilitation to participate in an "ICF Advisory Board," hosted by the regional Medicare Administrative Contractor, Palmetto GBA.

- The new Fourth Edition of the popular textbook Handbook of Counseling Psychology (2008) introduces the ICF to the Counseling Psychology community.
- A new "ICF / CIRRIE Crosswalk" tool is available for your use: you can search the CIRRIE database of international rehabilitation publications using two-level ICF codes.
- A new book, Focus on Disability: Trends in Research and
 Application, Volume II (2007), edited by Dr. Thilo Kroll from the
 University of Dundee, incorporates 4 chapters referring to the ICF.
- The U.S. National Center on Physical Activity and Disability prepared a digest for exercise trainers entitled "Use of the ICF to Prepare Individualized Exercise Prescriptions for People with Disabilities."
- The British Columbia Ministry of Children and Family Development and the Sunny Hill Centre for Children in Vancouver, B.C., have developed an on-line modular short course on the ICF and how it can be used among children with special needs.
- <u>Teams of Speech-Language Pathologists delivered two ICF-oriented presentations at the November, 2007 Convention of the American Speech-Language-Hearing Association, conducted in Boston.</u>
- <u>The WHO-FIC Functioning and Disability Reference Group conducted</u> its midyear meeting in Zurich, discussing many ICF topics.
- <u>The March, 2008 International Conference on Ectodermal Dysplasias</u> Classification hosted a presentation about the ICF-CY.
- <u>Continuing success: Elsevier's Disability and Health Journal is underway, with a noteworthy Editorial Board.</u>
- <u>Call For Papers: A special issue on the ICF is planned for 2009 in Alter, a new European Journal of Disability Research.</u>

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1) 2008 North American Collaborating Center Conference on the ICF

The Early Bird Registration period has been extended to May 31, 2008. Please join us August 26-27 in Québec City for this year's ICF Conference!

The North American Collaborating Center (NACC) for the WHO Family of International Classifications sincerely invites you to participate in the 14th Annual NACC Conference on the ICF, to be held in Québec City, Québec.

The Canadian Institute for Health Information (CIHI), Statistics Canada, and the U.S. National Center for Health Statistics are pleased to serve as your hosts for the 2008 ICF Conference.

NACC is also pleased to announce that the "Early Bird" registration rate is available until May 31, 2008. Read the updated registration details here.

The ICF Conference dates will be **Tuesday and Wednesday**, **August 26** and **27**, **2008**, in Québec City. The ICF Conference will begin with a Welcoming Reception on Monday evening, August 25, and then full-scale conferencing activities start in earnest the following morning, Tuesday, August 26.

The theme for the 2008 NACC Conference on the ICF will be "Evaluating Social Participation: Applications of the ICF and ICF-CY."

Although the Call For Abstracts is now closed, NACC is pleased to report that the developing program for the ICF Conference will be robust, diverse, and scientifically innovative. More than 50 authors will deliver presentations about applying the ICF in clinical practice, surveys, and in rehabilitation systems during the ICF Conference.

We encourage everyone in the North American ICF Community to take advantage of this unique conference partnership opportunity. This year, NACC is honored to host the ICF Conference in conjunction with the 21st World Congress of Rehabilitation International (RI). The RI World Congress is a quadrennial event; the 20th World Congress was held in Oslo, Norway in June, 2004. Previous Congresses have been conducted in Winnipeg (1980), Lisbon (1984), Tokyo (1988), Nairobi (1992), Auckland (1996), and Rio de Janeiro (2000).

The RI World Congress is an enormously important international event, worth attending on its own merits. This year, the NACC Conference on the ICF will be conducted as a separate but parallel, concurrent event during the week in which the RI World Congress will be underway, August 23-28, 2008, at the same conference venue, the Québec City Convention Centre. That means this year's

NACC ICF Conference will provide you with unique opportunities to share your knowledge about the ICF among delegates to the RI World Congress from around the globe, and to learn from them, too.

The theme for the 21st World Congress will be "Disability Rights and Social Participation: Ensuring a Society for All." This means there will be substantial thematic overlap between the NACC ICF Conference and the RI World Congress, both of which will address Social Participation this year --- determining what Social Participation means, measuring it accurately, and enhancing the degree to which persons with disabilities can fully participate in their social environments.

According to its website, RI "is a global and diverse organization of persons with disabilities, NGOs, government agencies, service providers and advocates who work together to advance the rights and inclusion of people with disabilities worldwide." RI was founded in 1922. Its headquarters are in New York City, with regional leadership around the world. Several thousand delegates typically attend the RI World Congress, therefore the Québec City event will be an important, timely conference about all aspects of rehabilitation and social participation among persons with disabilities.

These websites describe both RI and the 21st World Congress:

http://www.riglobal.org/index.html http://www.riguebec2008.org/

On that website for its 2008 Québec City World Congress, RI has asserted that their theme is not only consistent with the organization's priorities, but also that it will spark "international dialogue on the implementation of the U.N. Convention on the Rights of Persons with Disabilities [2006]. The reality of disability is not only the problem of a social minority, since disability affects almost every person in society at some point in their lives." Surely, this conference theme is fully consistent with the ICF, too, therefore our NACC elected to accentuate that consistency by adopting a similar conference theme in 2008, related to Social Participation.

NACC is also pleased to announce that a "Joint Plenary Session" between the two conferences has been arranged. On Tuesday, August 26, Professor David Gray from the Washington University School of Medicine, Program in Occupational Therapy, will deliver one of the 9 Keynote Speeches during the RI World Congress, timed in such a way that our NACC ICF Conference participants will be conferring and able to participate. Professor Gray is a longtime advocate for the ICF, and served as a member of the team contributing to the revision of the ICIDH during the 1990s. Professor Gray's Plenary Session address will be entitled "Community Receptivity for People with Disabilities: Measures for use in Assessing and Implementing Change."

NACC would like to acknowledge the substantial contributions already invested by Professor Patrick Fougeyrollas from Université Laval in Québec, not only on behalf of NACC and its interests, but also for RI itself. As one of the local hosts, Patrick has been preparing for the 2008 RI World Congress for several years, since the Oslo meeting in 2004.

Registering for the ICF Conference

Regarding the registration procedures, NACC is pleased to announce that the "Early Bird" registration period has been extended until May 31, 2008.

The Rehabilitation International World Congress Committee will be handling the conference registrations for **all** the NACC ICF Conference events **and** the RI World Congress events.

To register, you can go online and use this RI web page: http://www.riquebec2008.org/ and click on "Registration" and "Rates" for the pertinent information on subsequent web pages.

Regarding the prices, registration for the NACC ICF Conference proper will be more expensive than in previous years, but your fee will purchase quite a lot of conference value.

Specifically, there will be a *Daily Registration Rate* (\$300.00 CDN per day, about \$296.00 USD). This is the RI World Congress daily rate, and it will remain the same until the Congress begins. There is no "Early Bird rate" or cut-off date for the Daily Registration Rate.

For persons who want to attend only the two NACC ICF Conference days (Tuesday and Wednesday, August 26 and 27), you should purchase two days' worth of the RI World Congress' Daily Registration, for a total of \$600.00 CDN. On any Congress day for which a registrant had purchased the Daily Registration, he or she will also be entitled to attend *any and all* of the events in either the RI World Congress or the NACC ICF Conference on those two days.

Pertinently, though, for nearly the same price, you can purchase the full registration for the entire RI World Congress, covering August 25 to 28, under the "Early Bird" rate until May 31, 2008, for only \$650.00 CDN total! (After May 31, the rate increases to \$750.00 CDN, and to \$850.00 CDN for on-site registration, although the Daily Registration Rate remains at \$300.00 CDN throughout the year.) This would enable you to attend both conferences. Therefore, you have a strong incentive to attend the full RI World Congress, on dates either preceding or following our NACC ICF Conference. Perhaps just as valuably, registrants primarily interested in the RI World Congress will be able to come over to the adjacent NACC ICF Conference on August 26 and 27, to learn and share as our partners in the disability sciences. This will be a unique opportunity for NACC

ICF Conference registrants and RI World Congress participants to achieve "critical mass" in essentially one venue. Join us!

If you are a dues-paying member of RI, you can enjoy a discounted registration rate for the full World Congress: \$590.00 CDN through the summer (\$690.00 CDN during on-site registration).

Please note that, although Rehabilitation International will accept credit card payment for the registration fee, they will only accept *Visa* and *MasterCard* or *EuroCard*; no other credit cards will be accepted for payment. Bank transfers are acceptable but will induce extra fees.

Please also note that RI has established a special reduced Student Registration Rate for persons in training. Students can attend the full World Congress at the rate of \$250.00 CDN. Moreover, RI offers a special rate for accompanying Personal Care Attendants (\$275.00 CDN).

Lodging Options During the ICF Conference

Regarding lodging, because the ICF Conference will be conducted in a conference center rather than a hotel, this year there will not be one particular hotel with a negotiated or preferred lodging rate for conferees. *You can select your own lodging*. Luckily, Québec City is a popular tourist destination with a large capacity of local accommodations, even in "high season" during the summer, but please, because of the Quadricentennial festivities, book early!

The RI World Congress website presents a short roster of nearby hotels, including estimated lodging prices, for your review and use in selecting a hotel. But this roster neither suggests endorsement by RI, nor provides any information about street location or disabled accessibility, therefore we provide the following RI web link "to get you started" in your selection process:

http://www.riquebec2008.org/ and click on "Accommodation." Also, below is the web link to the Québec City Tourism's "Accommodation" website: http://www.quebecregion.com/e/hotels.asp.

The venue will be the Québec City Convention Centre. The Centre's street address is; 1000, boulevard René Lévesque Est, Québec City, QC, Canada, G1R 2B5.

The Convention Centre also provides its own "Accommodations" website: http://www.convention.gc.ca/tiki-index.php?page=attendees accomodations.

On that Internet page, the Convention Centre has indicated that "16 superior quality hotels are within walking distance from the Centre, two of which are linked to the Centre by underground passageways, offering a total capacity of

(nearly) 3,500 rooms and suites." The Convention Centre website asserts all its hotel and conference facilities are accessible.

Throughout the summer, you can also find out about any updated information for the ICF Conference, and in due course a rendering of the Preliminary Program, at the following website, maintained by CIHI:

http://www.cihiconferences.ca/icfconference/#

NACC looks forward to welcoming you to the 14th Annual ICF Conference, in conjunction with our RI partners, for this unusual, valuable conference event. We encourage your participation!

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2) WHO – UN ESCAP Training Manual on Disability Statistics

The new *Training Manual* is now available, and it is based on the ICF.

The North American Collaborating Center encourages all readers to take advantage of the new *Training Manual on Disability Statistics*, released in March, 2008. WHO prepared the new Manual, in cooperation with the Statistics Division of the United Nations Economic and Social Commission for Asia and the Pacific (UN ESCAP). The U.N. Statistical Institute for Asia and the Pacific also contributed to the Manual. The Government of the Republic of Korea generously provided funding for the project that led to publication of this Manual. The Australian Bureau of Statistics also provided valuable technical support.

You can download a .PDF copy of the 242-page Manual at this website:

http://www.unescap.org/stat/disability/manual/index.asp

The new Manual has several purposes, and responds to different global and regional initiatives pertaining to disability statistics. The Preface makes these purposes and initiatives more explicit, particularly in terms of the ICF:

"To make people count, we have to count people right.' This notion is of particular relevance for the area of disability statistics, which until today is challenged by a substantial lack of accurate and comparable data. Few countries in the Asia Pacific region collect information on disability regularly through censuses or surveys. In countries where information is collected, it is often done without consideration of international standards or focuses on only disability in terms of predefined categories of impairments (e.g. people who

are blind, deaf, paraplegic or intellectually disabled). As a result, many countries in the Asia Pacific region have very limited and often non-comparable information about the extent of disability and the lived experience of person with disabilities and their needs.

The demand for more standardized disability statistics in the Asia Pacific region has increased significantly over the years. The Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for Persons with Disabilities in Asia and the Pacific (BMF) and its supplement, the Biwako Plus Five urges governments to develop national disability data systems using international standards and methodologies and revisit their current definitions of disability. The recently adopted Convention on the Rights of Persons with Disabilities and its Optional Protocol (CRPD) set the tone, at the global scale, of the broader approach to disability, which emphasizes the affect of environmental and attitudinal barriers on disability. CRPD calls for appropriate data collection on disability which would give effect to its implementation.

In response to these needs, the World Health Organization (WHO) and the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) have taken initiatives and implemented a joint project on improving disability statistics and measurement in the region by promoting a common definition and methodology based on the International Classification of Functioning, Disability and Health (ICF). It is against this background that this publication was prepared.

This training manual intends to enhance the understanding of the ICF-based approach to disability measurement. It provides an overview of the ICF framework as well as guidelines on how to operationalize the underlying concepts of functioning and disability into data collection, dissemination and analysis.

This publication will benefit not only statisticians but also a wider range of national and international users of data on disability. This broader influence will result from the wide applicability of the standards, methodologies and best practices covered by the manual. It is hoped, that the manual will assist in stimulating more disability data collection in accordance with international standards and data dissemination for both national and international disability policy analysis, formulation and evaluation worldwide" (pg. ii).

WHO and ESCAP designed the Manual both as a textbook for classroom teaching or self-paced learning, or as a guidebook for teams actually collecting and analyzing data sets. A review of the chapter titles reveals the structure of the Manual, and illustrates that it is fundamentally based within the ICF:

- "Disability Statistics: Why Are They Important and What Does ICF Add?
- "The ICF Framework"

- "Data Collection Methods and Instruments"
- "Using ICF in Survey and Census Design"
- "Survey / Census and Administrative-Based Data Collection Development: Planning and Measurement Issues"
- "Instrument Development"
- "Organizing the Fieldwork"
- "Processing the Data"
- "Analysing and Disseminating Disability Statistics"
- "Disability Statistics: Key to Sound Policy Formulation"

Throughout the Manual, comparisons have been drawn to other WHO or UN disability measurement activities (e.g., WHODAS, DISTAT), to demonstrate that earlier initiatives had been worthwhile but incomplete without the features now inherent in the ICF. In partial response to the question posed by the title for Chapter 1, "What Does the ICF Add?" particularly in the Asia Pacific region, we read that "The experience of integrating the ICF concepts into disability data collections has been that [the] disability phenomenon has been described with greater clarity and precision." Moreover, the Manual pointed out that current measurements only provide widely divergent estimates of disability prevalence, which leads to these straightforward observations:

"It is very hard to believe that these differences in prevalence are based in reality. It is more likely that they result from using different definitions of disability. The data for the different countries cannot be compared because they do not follow the same concept.

Without reliable demographic profiles of persons with disabilities, where they live and what problems they experience, the prospects for developing and improving national plans and disability policies remain poor. Furthermore, without basic estimates of prevalence in terms that are comparable across the ESCAP region, it is difficult to see how the goals in the BMF [Biwako Millennium Framework] and the Biwako Plus Five can be monitored, let alone achieved. This issue of non-comparable standards applied in the measurement and collection of disability information is precisely why implementation of the ICF is so important" (pg. 6).

The Manual acknowledged the parallel work of the Washington City Group on Disability Statistics. The Manual benefited from the experiences among countries that participated in the pilot-testing in 2005 of ICF-based questionnaire items developed by WHO and the Washington Group. NACC commends the authors and publication team members who contributed to this new Manual, and encourages all members of the North American ICF community to become familiar with it. Good reading!

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3) ICF Special Issues in Recent Speech-Language Pathology Journals

Two clinical journals have recently devoted special issues to the ICF, featuring many international authors.

Two journals in the fields of Speech-Language Pathology and Communication Disorders have recently published special issues devoted completely to applications of the ICF in those fields. The North American Collaborating Center would like to encourage your readership of these special issues, and also to commend the editors and authors for their outstanding work.

The first journal, the *International Journal of Speech-Language Pathology*, has marked its tenth anniversary by changing its name from *Advances in Speech-Language Pathology* to the new *IJSLP*. In her editorial announcing the new name and the ICF special issue, the Editor, Professor Sharynne McLeod from Charles Sturt University in Bathurst, New South Wales, Australia, wrote that "(O)n this significant milestone the name has been changed to reflect the increased internationalization of the journal. . . . I am very pleased that this first issue provides a truly international focus by considering the application of the World Health Organization's *International Classification of Functioning, Disability and Health* to speech-language pathology" (pg. 1). The special issue contains 11 articles about these ICF applications. We present the roster of articles below.

The second journal, *Seminars in Speech and Language*, has an editorial board whose members are based in the U.S. *Seminars* publishes quarterly, with two issues per year devoted to adult impairments, and the other two issues devoted to children's speech and language problems. It is more directed toward enhancing clinical practice among Speech-Language Pathologists, therefore the articles in this ICF special issue focus on assessment, risk factors, case examples that illustrate treatment modalities, and intervention strategies. The ICF articles in this special issue are each oriented to a particular disorder, for example, fluency disorders, and communication following laryngectomy. We present the roster of articles from the November, 2007 special issue below.

Our American ICF colleague Professor Travis Threats, Associate Professor and Chair of the Department of Communication Sciences and Disorders at Saint Louis University, contributed to both journals' special issues as both an author and editor. Travis also alerted NACC about their being published, for which we are thankful. Regarding the special issue in *Seminars*, Travis wrote to NACC that "We [the editors] designed it to be a 'book' on ICF and communication disorders, with the advantage of going through [the] journal

review process, and also enabled to be more accessible to more people. For example, if [a reader is] just interested in the ICF and stuttering, [he or she] could only order and download that article [from Seminars]. . . . We had it disorder-specific. That is, ICF and dementia, dysphagia, child language disorders, voice disorders, etc." Regarding the special issue in the *IJSLP*, Travis wrote that "(U)nder its current editor, Dr. Sharynne McLeod, for the past few years it has truly become a premier international journal, with its last issue under [the former] name having authors from 12 different countries. Thus we are proud to be [involved in] its inaugural issue, and obviously think [the ICF topic] is the best type of issue to be the first" (personal correspondence, January, 2008).

You can review the Table of Contents and article abstracts for the *IJSLP* special issue at the following publisher's website:

http://www.informaworld.com/smpp/title~content=g789609045~db=all

You can also review the Table of Contents and abstracts for the *Seminars* special issue at this publisher's website:

http://www.thieme-connect.com/ejournals/toc/ssl/7677

Here are the titles and author names from the *IJSLP* special issue:

- "An introduction to the International Classification of Functioning, Disability and Health (ICF) for speech-language pathology: Its past, present and future" Estella Ma, Travis T. Threats, Linda E. Worrall
- "The ICF body functions and structures related to speech-language pathology" Jane McCormack, Linda E. Worrall
- "The ICF activities and participation related to speech-language pathology" Robyn O'Halloran, Brigette Larkins
- "The ICF contextual factors related to speech-language pathology"
 Tami J. Howe
- "The contribution and impact of the International Classification of Functioning, Disability and Health on quality of life in communication disorders"

 Madeline Cruice
- "Use of the ICF for clinical practice in speech-language pathology"
 Travis T. Threats
- "Speech, hearing, and communication across five national disability surveys: Results of a DISTAB study using the ICF to compare prevalence patterns" Kristine A. Mulhorn, Travis T. Threats
- "The use of the ICF in speech-language pathology research: Towards a research agenda" Linda E. Worrall, Louise Hickson
- "Professional associations' role in advancing the ICF in speech-language pathology" Janet E. Brown, Amy L. Hasselkus
- "The ICF as a framework for interdisciplinary doctoral education in rehabilitation: Implications for speech-language pathology" Elizabeth Skarakis-Doyle, Philip C. Doyle
- "The ICF-CY and children with communication disabilities"

Sharynne McLeod, Travis T. Threats

Here are the titles and author names from the *Seminars* special issue:

- Foreword: "The International Classification of Functioning, Disability and Health (ICF) in clinical practice" Audrey L. Holland
- "The International Classification of Functioning, Disability and Health (ICF) in clinical practice" Estella Ma, Linda E. Worrall, Travis T. Threats
- "Application of the ICF in aphasia" Nina Simmons-Mackie, Aura Kagan
- "Application of the ICF and ICF-Children and Youth in children with speech impairment" Sharynne McLeod, Jane McCormack
- "Application of the ICF in children with language impairments" Carol Westby
- "The ICF and dementia" Tammy Hopper
- "Older adults with acquired hearing impairment: Applying the ICF in rehabilitation" Louise Hickson, Nerina Scarinci
- "Application of the ICF in communication after total laryngectomy"
 Tanya L. Eadie
- "Application of the ICF in reduced speech intelligibility in dysarthria"
 Allyson D. Dykstra, Mark E. Hakel, Scott G. Adams
- "Application of the ICF in fluency disorders" J. Scott Yaruss
- "Use of the ICF in dysphagia management" Travis T. Threats
- "The application of the ICF in cognitive-communication disorders following traumatic brain injury" *Brigette Larkins*
- "Application of the ICF in voice disorders" Estella Ma, Edwin Yiu, Katherine Verdolini Abbott

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4) "Assessment Protocol to Identify Environmental Barriers to Communication"

The U.S. National Institute on Deafness and Other Communication Disorders recently awarded a "Small Business Innovation Research" grant in the field of Speech-Language Pathology that refers to the ICF.

In the United States, a special federal grant program known as the "Small Business Innovation Research" (SBIR) program is available to scientific investigators and product-oriented entrepreneurs who competitively propose to develop and test innovative tools or products in a "small business incubator," for subsequent introduction into their appropriate marketplaces. SBIR funding is available for product development in many subject areas, for example, in

transportation, commerce, housing, law enforcement, and health and medicine. Although each application is peer-reviewed for its scientific merit, the emphasis in SBIR funding is on developing marketable products, not conducting research. In health and medicine, the National Institutes of Health is the largest source of SBIR funding among all U.S. government agencies.

The North American Collaborating Center recently learned that, to our knowledge, the first-ever ICF-oriented SBIR grant has been awarded! We want to thank Professor Travis Threats from Saint Louis University for alerting NACC about this important milestone. As a professor in Communication Disorders, Travis is also serving as a member of this project's Advisory Panel.

Margaret Calkins, Ph.D., from IDEAS Consulting, Inc., in Kirtland, Ohio, serves as the Principal Investigator in an SBIR project entitled "Assessment Protocol to Identify Environmental Barriers to Communication." The National Institute on Deafness and Other Communication Disorders, which is one of the Institutes within NIH, awarded this SBIR grant in December, 2007. Dr. Calkins founded IDEAS, Inc., in 1991; the acronym stands for "Innovative Designs in Environments for an Aging Society." One of the Specific Aims of the SBIR project will be "to develop a new and innovative Communication Toolkit -- 'Environmental Interventions for Dementia' -- that will enable speech-language pathologists to identify environmental barriers and facilities and recommend effective environmental interventions to improve communication of individuals with dementia in long-term care settings." The emphases on environmental barriers and interventions have been drawn directly from the ICF.

The project will also involve demonstrating the effectiveness of the Toolkit, and developing a marketing plan for its eventual introduction into the highly specialized market for products related to dementia patients. In their project abstract, the investigators wrote "The Toolkit will include: (1) a Training Module with video; (2) an Assessment Protocol; (3) measurement tools; and 4) user manual." Upon developing the prototype, this project will entail a panel of about 30 Speech-Language Pathologists participating as study subjects in the evaluation of the training module, using a pre- and post-test design. Subsequently, a smaller set of SLPs would be trained in the Assessment Protocol. The investigators will measure quantitative changes in the SLPs' clinical behavior that might be associated with their having participated in the Training Module, such as "the number of environmental interventions they recommend in their care plans." The overall goal will be to "expand the capacity of SLPs to reduce environmental barriers to communication with care recipients."

This SBIR project will continue throughout 2008 and would undergo competitive grant renewal procedures before entering its later phases, when the evaluated Toolkit would be prospectively ready for actual marketing. The NIH grant number this year is 1R43DC008916-01A1.

You can correspond with Dr. Calkins at this E-Mail address: mcalkins@ideasconsultinginc.com. You can also read about IDEAS Consulting, Inc., on their website, at: http://www.ideasconsultinginc.com/.

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5) Continuing Call for ICF Reviewers for APA "Procedural Manual"

The American Psychological Association invites your on-line review of the "Body Functions" portion of the revised "Clinical Manual."

As NACC announced in the January, 2008 edition of this ICF Newsletter, the American Psychological Association (APA) continues to extend its sincere invitation to persons familiar with the ICF to participate in APA's On-line Review of its forthcoming publication entitled *Procedural Manual and Guide for a Standardized Application of the ICF: A Manual for Health Professionals.* In its manuscript form, sometimes this publication is also referred to by its short-hand names, "the Procedural Manual" or "the Clinical Manual." The Manual, initially released as a monograph in 2003, primarily will become an electronic product.

As implied by its full title, the Manual is designed for making applications of the ICF in various clinical settings as consistent as possible. Although the APA is the leading organization in the development of the Manual, other collaborating professional associations include the American Speech-Language Hearing Association, the American Occupational Therapy Association, the American Physical Therapy Association, the National Association of Social Workers, and the American Therapeutic Recreation Association. This suggests that the Manual would be useful not only in psychological clinical settings or among psychologists, but also among multidisciplinary team members in nearly any acute, rehabilitation, or long-term care setting.

The On-line Review is necessary and valuable because it can efficiently induce the clinical knowledge among these various kinds of health professionals into the type of standardization that the Manual will ultimately provide in real-world settings. A reviewer does not have to be a clinician, and anyone with substantial knowledge of the ICF is invited to participate, but clinicians are particularly invited to participate and lend their specialized knowledge.

At this time, APA has released only one component of the ICF for the Online Review, the Body Functions domain. In the near future, APA will release additional ICF domains for the On-line Review. The Manual will be oriented in a manner that imitates the domain structure of the ICF. A reviewer would analyze the draft text about how to apply specific ICF Body Functions codes in clinical

settings, rather than the ICF codes themselves; this APA project does not entail any revisions to the ICF itself.

Please participate! Readers of this ICF Newsletter constitute the primary "target audience" for this On-line Review opportunity. Contributing reviewers will have the chance to be recognized within the final published versions. This is an enormously important activity for the broader development of clinical applications of the ICF. Please participate!

Dr. Lynn Bufka, APA Assistant Executive Director for Practice Research and Policy, and Omar Rehman, Project Manager for the Manual review, encourage reviewers to visit this APA project website: http://icf.apa.org/. Lynn informed us that "Reviewers must register to participate in the evaluation process but once registered, they can enter and exit the website at their convenience and can read or comment on any or all of the available content."

Dr. Geoffrey Reed joined Bufka and Rehman as authors of a helpful 4-page paper outlining the Manual review, presented during the 2007 Annual Meeting of the WHO Family of International Classifications (WHO-FIC) Network. The paper is available at this website link:

https://crs.sanita.fvg.it/WHO/Documents/WHOFIC2007 D015.pdf

Within that paper, the authors explained "The APA, along with its collaborators, has developed a database of individuals with expressed interest in the ICF and its clinical applications. Individuals are regularly added to this database as their interest in the ICF becomes known. . . . While the majority of the individuals are from the U.S., individuals from around the world are invited to participate in the evaluation process. We recognize that the content of the Manual is limited by the worldview of the contributors, but efforts have been made to provide universal examples and information that [are] useful in a wide variety of health care applications. It is hoped that this Manual will be adapted for use in other health care systems, but it is understood that much of the content has been developed by experts most familiar with North American health care. Reviewers who can provide commentary regarding the universality of concepts and information are desired" (pg. 3).

The authors also explained that this NACC ICF Newsletter is a part of their overall recruitment strategy for obtaining a full complement of Manual reviewers. "The review process has been designed to provide easy electronic access to all of the Manual content. In addition to soliciting feedback on the content itself, we are also soliciting feedback on the electronic format. We anticipate that future uses of the Manual content will not only be in print format but also in electronic format. We have discussed various possibilities for sharing the Manual content with other ICF products in order to provide a suite of products to facilitate use of the ICF in clinical applications" (pg.3).

The authors provided a helpful reference to a peer-reviewed paper they had previously published, regarding clinical applications of the ICF, as potential background information for reviewers seeking more information about direct applications of the Manual in practice settings:

Reed GM, Lux JB, Bufka LF, Trask C, Peterson DB, Stark S, Threats TT, Jacobson JA, Hawley JW. Operationalizing the International Classification of Functioning, Disability and Health (ICF) in clinical settings. *Rehabilitation Psychology* 2005; 50(2):122-131.

Remember to register as a reviewer at this website:

<u>http://icf.apa.org/</u> , or similarly, http://icf.apa.org/splash.cfm .

. . . and you can correspond with Dr. Bufka at this E-Mail address: <u>LBufka@apa.org</u> for further information.

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6) "ICF Spotlight" on Kristine A. Mulhorn, Ph.D., M.H.S.A.

Occasionally in the NACC ICF Newsletter, we turn the "ICF Spotlight" onto a North American scientist or other professional, in recognition of their contributions to the development or implementation of the ICF in the U.S. or Canada. Our goal is to expand and enhance our North American ICF community through networking, collegiality, and *esprit de corps*.

In this issue of the Newsletter, we are proud to feature in that Spotlight our colleague Kristine A. Mulhorn, Ph.D., M.H.S.A., from Flint, Michigan.

Currently Kristine serves as an Associate Professor of Health Care in the Department of Health Sciences and Administration at the University of Michigan at Flint. Professor Mulhorn's primary teaching responsibilities are in the areas of health administration, health policy, aging, disability studies, and international health. Her research interests extend from disability studies to Alzheimer's disease caregiving, alternative approaches to caring for elderly patients, research methodologies, and estimating health expectancy. Professor Mulhorn earned her doctoral degree in Sociology from the University of Delaware, and prior to that she earned the Master of Health Services Administration degree from the School of Public Health at the University of Michigan in Ann Arbor.

Pertinently, Kristine has had a long involvement investigating crossnational comparisons of disability statistics generally, and measurements of functioning among elderly members of the populations of different nations. As a fluent speaker of Japanese, it should come as no surprise that Kristine has a substantial interest in comparing functional status measurements between the American and Japanese populations.

That interest in cross-national comparisons has become a hallmark in Kristine's academic career. Dedicated readers of this ICF Newsletter might remember that we have mentioned Kristine's work in international disability statistics in several Newsletter editions over the years.

In fact, Kristine holds the unusual honor of having participated in two important international disability statistics measurement initiatives during the last decade: DISTAT and DISTAB. DISTAT is the United Nations Disability Statistics Database, a global database incorporating statistics, indicator variables, and text from various sets of national data reflecting estimates of country-level disability prevalence. Earlier this decade, Kristine collaborated with our U.N. Statistics Division colleagues to analyze census data from many countries to generate such estimates, commenting at each stage on the lack of uniformity or consistency in determining a suitable definition of disability for measurement purposes. That experience bridged the period between the ICIDH and the ICF, which illustrates Kristine's longevity in this field. DISTAB (for "Disability Tabulations") had been a U.S. National Center for Health Statistics initiative. It involved investigators from Canada, France, the Netherlands, South Africa, the U.N. Statistics Division, and the U.S., including Kristine. The members of DISTAB set themselves to the task of making useful cross-national comparisons of disability prevalence estimates, during the period in which the ICF conceptual framework would have influenced the construction and administration of the survey and census questions that became the data source for DISTAB.

In our November, 2002 edition of this ICF Newsletter, we also featured an entry submitted by Kristine about the roster of American and Canadian college and university courses that incorporated or referred to the ICF at that time. Naturally, curricula change, and teaching about the ICF is now pursued more frequently in professional schools or allied health programs than in general university courses, but Kristine's initial work revealed that there had been already substantial new interest at the university level in the then-brand-new ICF.

You can review Professor Mulhorn's University of Michigan-Flint Department of Health Sciences and Administration faculty profile at this website, on page 3 of 4 pages:

http://www.umflint.edu/hsa/Faculty Profiles.htm

Below this entry we have provided a short bibliography of some of Professor Mulhorn's contributions to the ICF literature. We previously referenced

one of the articles above in this ICF Newsletter, pertaining to the ICF special issue in the *International Journal of Speech-Language Pathology*. We also encourage readers to correspond with Kristine at the following University of Michigan-Flint E-Mail address: kmulhorn@umflint.edu.

- Swanson G, Carrothers L, Mulhorn KA. Comparing disability survey questions in five countries: A study using ICF to guide comparisons. Disability and Rehabilitation 2003 (June 3-17); 25(11-12):665-675.
- Mulhorn KA. Addressing recommendations for increasing the rate of response by persons with disabilities: A comparison across six national surveys. In Kroll, T (ed.), <u>Towards Best Practices for Surveying People</u> with Disabilities, Volume I; Hauppague, NY: Nova Science Publishers, Inc., 2007, pp. 1-11.
- Mulhorn KA. Cross-walking ICF to the TMIG-IC -- Tokyo Metropolitan Institute of Gerontology's Index of Competence: An application of ICF in community-living elderly. In Kroll T (ed.), <u>Focus on Disability: Trends in</u> <u>Research and Application, Volume II</u>; Hauppague, NY: Nova Science Publishers, Inc., 2007, pp. 23-30.
- Mulhorn KA, Threats TT. Speech, hearing, and communication across five national disability surveys: Results of a DISTAB study using the ICF to compare prevalence patterns. *International Journal of Speech-Language Pathology* 2008 (February); 10(1-2):61-71.

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7) Briefly Noted: ICF News of Interest

 Special invitation to persons in the western U.S. who are involved in rehabilitation to participate in an "ICF Advisory Committee," hosted by the regional Medicare Administrative Contractor, Palmetto GBA.

From our American ICF colleague Harry Feliciano, M.D., M.P.H., Regional Director of Medical Affairs for Palmetto GBA, a large fiscal intermediary and medical claims administration firm operating in the U.S., comes this unique opportunity for one or more persons to contribute to ICF-oriented health policy development. There is a regional requirement, though. Here is the text of Dr. Feliciano's announcement:

"Palmetto GBA, a wholly-owned subsidiary of Blue Cross Blue Shield of South Carolina, has been selected by the Centers for Medicare and Medicaid Services (CMS) to serve as the new [Parts A and B] Medicare Administrative Contractor for Jurisdiction 1 (J1), which includes the states of California, Hawaii and Nevada, the territories of American Samoa and Guam, and the Northern Mariana Islands. In this capacity Palmetto GBA will be, among other things, developing education to help both physician and non-physician health care providers navigate the complex Medicare continuum of care. While administratively Medicare does not require use of the ICF, Palmetto GBA has successfully utilized ICF-based care scenarios to communicate coverage policy and help health care providers make administrative and clinical decisions."

"Palmetto GBA is seeking individuals in the J1 region with experience using the ICF and providing rehabilitation services (e.g., Physical Medicine and Rehabilitation, Physical Therapy, Occupational Therapy, Speech-Language Pathology, and Respiratory Care) to the Medicare population. The individuals would serve on an *ad hoc* advisory committee providing feedback to Palmetto GBA's Medical Affairs area on proposed policy and education. Those interested in serving on the proposed advisory committee should contact Dr. Harry Feliciano at the address below."

Harry Feliciano, M.D., M.P.H. Director, J1 Medical Affairs Palmetto GBA Mail Code AG-300, Post Office Box 100238

Columbia, SC 29202-3238 Phone: (803) 763-5007

E-Mail: Harry.Feliciano@PalmettoGBA.com

Websites:

http://www.palmettogba.com/palmetto/aboutarea.nsf/index.htm http://www.palmettogba.com/palmetto/j1.nsf/DocsCat/Home

Palmetto GBA "Going Beyond Diagnosis" Series website: www.PalmettoGBA.com/rhhi/GoingBeyondDiagnosis

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The new Fourth Edition of the popular textbook *Handbook of Counseling Psychology* (2008) introduces the ICF to the Counseling Psychology community.

From our American ICF colleague David B. Peterson, Ph.D., C.R.C., professor in the Department of Special Education and Counseling at California

State University, Los Angeles, comes the timely announcement that one of the most popular textbooks in Rehabilitation Counseling has been recently revised, incorporating a new chapter on the ICF. John Wiley & Sons, Inc., recently published the 4th edition of its Handbook of Counseling Psychology, featuring the original editors, Dr. Steven Brown from Loyola University and Dr. Robert Lent from the University of Maryland, and several new sections and chapters.

Specifically, Professor Peterson from CSULA and Professor Timothy R. Elliott from Texas A&M University authored the new chapter entitled "Advances in Conceptualizing and Studying Disability," in the textbook's section on "Diversity and Multicultural Psychology." Professor Elliott also serves as the editor of the prominent journal *Rehabilitation Psychology*. According to Dr. Peterson, the new chapter "features the ICF and its influence on the conceptualization of disability around the world." Peterson and Elliott "designed the chapter to introduce the ICF to the counseling psychology community as a new way to talk about disability, health and functioning" (personal correspondence, March, 2008).

The new textbook's assigned number is ISBN: 978-0-470-09622-2, and you can view the publisher's web page for the new volume at this website: http://www.wiley.com/WileyCDA/WileyTitle/productCd-0470096225,descCd-description.html

You can contact Professor David Peterson at this E-Mail address: dpeters3@calstatela.edu .

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 A new "ICF / CIRRIE Crosswalk" tool is available for your use: you can search the CIRRIE database of international rehabilitation publications using two-level ICF codes.

From our American ICF colleagues Professor John Stone and Marcie Daumen at the University of Buffalo's Center for International Rehabilitation Research Information and Exchange (CIRRIE) comes this important announcement: a new "ICF to CIRRIE Crosswalk" is now available on the CIRRIE website for your use. With the new Crosswalk tool, any user can search through the substantial electronic database of rehabilitation research books and articles maintained by CIRRIE, using not just prose keywords but actual 2-level ICF codes. The Crosswalk tool recognizes the ICF codes as a representation of particular searchable keywords, and then conducts the search conventionally. The tool outputs a roster of published articles or books that are catalogued and cross-referenced within the regular CIRRIE database. The user would select

from that roster for further research, or refine their search terms. The CIRRIE database mainly covers rehabilitation research conducted outside the U.S.

The ICF / CIRRIE Crosswalk can be accessed at this website: http://cirrie.buffalo.edu/icf/crosswalk.php

For example, if a user enters "d115," the ICF Activities and Participation code for "Listening," the Crosswalk first returns more options for selecting from the existing set of CIRRIE subject headings. In this example, the headings include Cognition, Intelligence, Perception and Sensory Research. The user can select a Boolean operator. An additional operation can involve the selection of a particular "Condition (or) Sub-Population" from a pull-down menu, which refines the overall search. This example search, conducted on the terms "d115," "Sensory Research," and "Females," yielded 2 recent articles for further review.

With the new Crosswalk tool, a user can also "go in reverse," too, utilizing a prose keyword from the CIRRIE Thesaurus to output a set of relevant ICF codes. For example, entering the Thesaurus term "Mobility" yields a selection of 6 ICF codes from Activities & Participation Chapter 4, Mobility. Moreover, a user can begin their searching by browsing ICF codes at the domain level, in other words, a user does not need to know a particular ICF code to begin searching.

The "reverse" CIRRIE to ICF Crosswalk function begins at this website: http://cirrie.buffalo.edu/icf/crosswalk.php?mode=reverse

The "All Codes" page, from which a user can select any ICF code, is at: http://cirrie.buffalo.edu/icf/crosswalk.php?list=all

Try this cool new tool! NACC applauds John Stone, Marcie Daumen, and all their CIRRIE colleagues for developing this and many other ICF-oriented tools within the CIRRIE database and website environment. Bravo!

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• A new book, Focus on Disability: Trends in Research and Application, Volume II (2007), edited by Dr. Thilo Kroll from the University of Dundee, incorporates 4 chapters referring to the ICF.

From our ICF colleague Dr. Thilo Kroll, Senior Lecturer at the School of Nursing and Midwifery, Alliance for Self-Care Research, at the University of Dundee in Scotland, comes the announcement of a new textbook with 4 chapters explicitly referring to the ICF. Dr. Kroll also serves as an Associate Director of the University of Dundee's Interdisciplinary Disability Research Institute. Thilo

has edited his second textbook for Nova Science Publishers, Inc., entitled <u>Focus</u> on <u>Disability: Trends in Research and Application, Volume II</u> (2007).

The new textbook features 4 broad sections, entitled "Disability Classification," "Health Care Service Delivery," "Health Education and Promotion," and "Living with Long-Term Disabling Conditions." Twenty-five authors from nearly a dozen countries have contributed 12 chapters within these 4 sections. The section on "Disability Classification" contains the 4 articles that refer to the ICF. Here are their titles and author names:

- "Linking the Barthel Index, Reintegration to Normal Living Index, and OARS-IADL to the ICF to Characterize Community-Dwelling Elders" Lise Poissant, Sara Ahmed, Nancy E. Mayo [N.B.: OARS-IADL is the "Older Americans Resource Scale for Instrumental Activities of Daily Living"]
- 2) "Cross-Walking ICF to the TMIG-IC -- Tokyo Metropolitan Institute of Gerontology's Index of Competence: An Application of ICF in Community-Living Elderly" *Kristine A. Mulhorn*
- "Evaluating the ICF as a Framework for Clinical Assessment of Persons for Assistive Technology Device Recommendations" Sajay Arthanat, James A. Lenker
- 4) "Application of the ICF Codes in Geriatric Assessment: Use of the ICF Qualifiers to Quantify Health Information" *Jiro Okochi, Tai Takahashi*

The new textbook's assigned number is: ISBN: 1-60021-792-3, and you can view the publisher's web page for the new volume at this website: https://www.novapublishers.com/catalog/product_info.php?products_id=5810

As a reminder, Dr. Kroll's first edited textbook for Nova Scientific Publishers had been entitled <u>Towards Best Practices for Surveying People with Disabilities</u>, <u>Volume I</u> (2007), for which David Keer, Paul Placek, Juliana Cyril, and Gerry Hendershot also served as co-editors. That textbook's ISBN number is ISBN: 1-60021-195-X, and you can view the publisher's web page at: https://www.novapublishers.com/catalog/product_info.php?products_id=4446

You can contact Thilo Kroll at this E-Mail address: t.kroll@dundee.ac.uk.

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 The U.S. National Center on Physical Activity and Disability prepared a digest for exercise trainers entitled "Use of the ICF to Prepare Individualized Exercise Prescriptions for People with Disabilities." Our American colleague Dr. James H. Rimmer, Professor in the Department of Disability and Human Development at the University of Illinois at Chicago (UIC), and Director of the National Center on Physical Activity and Disability (NCPAD), has informed NACC that NCPAD now hosts on its website a brief digest for exercise trainers referring to the ICF. This monograph is entitled "Use of the ICF to Prepare Individualized Exercise Prescriptions for People with Disabilities," and it was prepared in 2006 by Amy Rauworth, M.S. Amy is the Associate Director of Operations and Exercise Physiology Research at the Center on Health Promotion Research for Persons with Disabilities, which includes NCPAD and other research centers at UIC.

Amy prepared this ICF monograph as an entry in the NCPAD Newsletter's "F.I.T.T. Column." The acronym stands for "Frequency, Intensity, Type and Time" and the words refer to various important characteristics of efficient exercising, toward optimal fitness. The F.I.T.T. Column is a regular feature of the NCPAD Newsletter, to which anyone can subscribe.

The monograph begins with the section entitled "Tailoring the Physical Activity Program for Success." Amy wrote, "Using the . . . ICF to prepare individualized exercise prescriptions for people with disabilities can provide a platform that allows the fitness professional to think outside the box and consider all factors that will contribute to the success of the exercise program. The ICF model will not only allow the fitness professional to tailor the program to the needs of the individual but it will [also] give a broader scope and depth to the measure of functional improvements that our clients will make" (pg. 1).

Following a brief description of the ICF, Amy prepared a useful illustration roughly mimicking the domain categorization in ICF, with specific exercise interventions or environmental modifications within each domain. Entitled "ICF Model and Cardiovascular Training for Stroke Survivors," this model even provides a set of Personal Factors that could influence the exercise outcomes of the hypothetical 72-year-old female stroke survivor depicted in the model. If an exercise trainer were to develop a similar ICF Model for one or more of their particular clients, it would be easy to develop a schematic for an individualized fitness plan that visually adheres to the ICF's own familiar interactive model, while still remaining specific to a particular chronic disease or health condition.

You can download this 4-page monograph at this NCPAD website: http://www.ncpad.org/fitt/fact_sheet.php?sheet=459&view=all&print=yes

Also, anyone can enroll to receive the monthly NCPAD Newsletter, which always provides interesting reading about fitness and disability:

http://www.ncpad.org/newsletter/newsletter.php?letter=current

You can contact Amy Rauworth and Professor Jim Rimmer at these E-Mail addresses, respectively: rauworth@uic.edu and jrimmer@uic.edu.

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• The British Columbia Ministry of Children and Family Development and the Sunny Hill Centre for Children in Vancouver, B.C., have developed an on-line modular short course on the ICF and how it can be used among children with special needs.

The British Columbia Ministry of Children and Family Development has developed a new on-line short training course about the ICF, designed as an "elearning" opportunity for many different types of clinicians who work with children with disabilities. The British Columbia Children's Hospital and Health Centre, and its affiliated Sunny Hills Health Centre for Children, both located in Vancouver, exhibit a commitment to professional continuing education in many topics, judging from the wealth of "e-learning" courses available to professionals on these agencies' websites. Their ICF short course is particularly enriching and original, although it had been posted in 2006 and pre-dates the publication of the new ICF-CY. It is a self-paced modular course with useful quizzes at the end of each module to determine the learner's overall degree of comprehension of the new material. The course is in English, and it would take about an hour to complete the material and quizzes. Moreover, instead of a glossary, this modular course presents definitions and pronunciations of newly-introduced terms right on the viewer's screen, for easier and quicker interpretation.

Anyone can access this ICF course at any of the following websites: http://www.bcchildrens.ca/Professionals/EducationTraining/ICF.htm

http://www.childdevelopment.ca/

http://www.cw.bc.ca/onlinecourses/sample/InternationalClass/interclass2_main_p001.htm

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 Teams of Speech-Language Pathologists delivered two ICF-oriented presentations at the November, 2007 Convention of the American Speech-Language-Hearing Association, conducted in Boston. Our American ICF colleague Professor Travis Threats, Associate Professor and Chair of the Department of Communication Sciences and Disorders at Saint Louis University, alerted NACC that he and several other communication specialists delivered one Poster Presentation and one seminar about the ICF during the November, 2007 Convention of the American Speech-Language Hearing Association (ASHA) in Boston.

On November 15, 2007, Travis joined Candace Vickers, M.S., from St. Jude Medical Center in Fullerton, CA, on a Poster Presentation entitled "Language Disorders in Adults: Measuring Increased Life Participation Associated with Attending an Aphasia Group." The authors had designed questionnaires and a set of structured interview protocols "based on relevant World Health Organization ICF codes for participation." Their abstract reported that their results "highlight the value of using the participation construct from the WHO in assessment to determine whether speech-language pathology interventions lead to meaningful life changes."

You can review the abstract and handouts for the Vickers-Threats poster presentation at the following ASHA websites:

http://convention.asha.org/2007/e_pop_profiles.cfm?session=1&session_id=817 23&class_id=77767

http://convention.asha.org/2007/handouts/1137_1084Vickers_Candace_107884_Nov13_2007_Time_110810AM.doc

Separately, Travis also participated with Canadian and American colleagues in a seminar entitled "Using A-FROM to Guide Outcome-Driven Aphasia Assessment and Intervention." The lead author on that presentation had been Aura Kagan from the Aphasia Institute in Toronto. The "A-FROM" represents the "Living with Aphasia: Framework for Outcome Measurement" model of outcome assessment in aphasia therapy, and that model is fundamentally based within the ICF, particularly in terms of participation. Bravo!

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 The WHO-FIC Functioning and Disability Reference Group conducted its midyear meeting in Zurich, discussing many ICF topics.

The World Health Organization's Family of International Classifications (WHO-FIC) Network's Functioning and Disability Reference Group (FDRG), the body assigned the tasks of reviewing proposals for updating the ICF, conducted its midyear meeting in Zurich in April, 2008. Ms. Ros Madden from Australia and

Dr. Gerold Stucki from Germany are the Co-Chairs. The FDRG has 8 Work Groups to investigate components of the ICF or its coding guidelines in greater detail, and some members of each of these Work Groups also met in Zurich.

The 8 Work Groups are named by their respective assignments:

- 1) Principles of Use, Coding Rules, and Guidelines
- 2) ICF Updates
- 3) ICF Implications for ICD
- 4) Measurement and Statistical Use of ICF
- 5) Educational Materials
- 6) Ethics and ICF
- 7) Environmental Factors
- 8) Terminologies and ICF

Although no reports have yet been generated from the midyear meeting, you can review earlier documents about the FDRG's progress and the tasks assigned to each Work Group in the following documents, which had been presented during the 2007 WHO-FIC Network Annual Meeting. The WHO-FIC Network's Italian Collaborating Center maintains the websites below.

Summary of the FDRG's recent work: https://crs.sanita.fvg.it/WHO/Documents/WHOFIC2007 C009.pdf

"Report to FDRG -- Project 3 -- ICF and ICD" https://crs.sanita.fvg.it/WHO/Documents/WHOFIC2007 D047.pdf

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• The March, 2008 International Conference on Ectodermal Dysplasias Classification hosted a presentation about the ICF-CY.

In March, 2008, in Charleston, South Carolina, the National Foundation for Ectodermal Dysplasias (NFED) conducted its international scientific conference on classifying the many manifestations of the Ectodermal Dysplasias (EDs). The EDs are a set of about 150 heritable disorders affecting the ectoderm, which is the outer layer of tissue in a developing baby. Children can survive into adulthood; it is not always fatal. At or shortly after birth, babies with one of the ED syndromes are affected primarily in their mouths, gums, baby teeth, hair, nails, sweat glands, and lips. The classification challenges stem from the fact that the course of any ED is influenced not only by genetics, but also by molecular, biochemical, functional, and social or environmental factors. Many

young adults with EDs face social participation challenges. Therefore, generally classifying the EDs could also suitably invoke the ICF.

Professor Rune Simeonsson from the University of North Carolina at Chapel Hill, one of the leading contributors to the new ICF-CY, delivered a presentation entitled "Ectodermal Dysplasias Classification: Contribution of the ICF-CY." In it, Professor Simeonsson proposed a "multi-axial" approach to classifying EDs, so that the clinical spectrum of the somatic status or outcomes of persons with EDs could be depicted on one axis, while the social participation challenges more aligned with ICF coding might be depicted on a separate axis. Moreover, the NFED also surveys parents, family members and other caregivers about the extent of social participation problems experienced by the young person with an ED and his or her family members. The NFED Family Needs Survey form might be amended to incorporate ICF coding in the near future.

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• Continuing success: Elsevier's *Disability and Health Journal* is underway, with a noteworthy Editorial Board.

In the January, 2008 edition of this ICF Newsletter, NACC reported that the first issue of the *Disability and Health Journal*, which has an orientation toward the ICF conceptual framework, had recently been published. NACC encourages readers of this ICF Newsletter to become familiar with the new journal, and to consider submitting manuscripts on ICF-oriented topics or research results for review. *Disability and Health Journal* is the official journal of the American Association on Health and Disability; it is published by Elsevier.

According to its "Aims and Scope," "Disability and Health Journal intends to advance the conceptual framework of the International Classification of Functioning, Disability, and Health to describe health and health related states, but will not limit the publications to this framework. The Disability and Health Journal will provide a forum for peer reviewed articles that identify, evaluate, and promote existing and emerging models of health care delivery or promotion, which contributes to the improvement of health care across the lifespan."

Moreover, they wrote "The focus of the *Disability and Health Journal* will be public health, health promotion, health education, wellness and prevention, and disability research. The *Journal* will incorporate population and clinic-based studies. The *Journal* would incorporate articles related to descriptions and analysis of disability domains and impairment groups, analysis and modeling of relationship between individual and environmental factors resulting in health and health related states, and conceptual articles about disabilities and health."

You can review the Table of Contents for current and archived issues of *Disability and Health Journal*, and the roster of Editorial Board members, at the following websites maintained by Elsevier:

http://www.disabilityandhealthjnl.com/home http://www.disabilityandhealthjnl.com/edboard

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Call For Papers: A special issue on the ICF is planned for 2009 in *Alter*, a new European Journal of Disability Research.

NACC has learned that the Editorial Board for the new journal *Alter*, a European Journal of Disability Research, has issued a Call For Papers for a planned special issue on the ICF, scheduled for publication in either 2009 or 2010. This journal is also published by Elsevier. In correspondence from the Editor-in-Chief, Henri-Jacques Stiker, NACC has learned that solicited or submitted articles for the proposed special issue should focus on "both theoretical and conceptual aspects" of the Classification. Authors should make efforts to evaluate "both strictness and consistency of concepts" in the ICF.

Alter is a quarterly peer-reviewed journal that observes disability and its variations. Alter "is an emblematic Latin word for all forms of difference, leaving open the question of their nature and expression." The journal "covers matters ranging from the individual to the environment, from impairment to participation, from discrimination to the exercise of citizenship. The European dimension means having a multi-cultural outlook; it means well-argued comparisons and useful scientific controversies that go beyond national boundaries."

Prospective authors interested in learning more about the planned 2009 special issue on the ICF should correspond directly with the publisher, Elsevier, at this e-Mail address: <u>alter@elsevier.com</u>. The Editorial Secretary for *Alter* is Mrs. Françoise Marchand, who is associated with the Federal Research Institute on Disability (Institut Fédératif de Recherche sur le Handicap) in Paris. Mrs. Marchand's E-Mail address is: fmarchand1@gmail.com.

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